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QUALITY OF LIFE OF PARENTS WHO HAVE CHILDREN WITH DISABILITIES

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Background: Parents who have children with disabilities are often reported to have physical and psychological distress related to caring for their children, thus affecting their quality of life (QOL). This study explored the QOL among parents who have children with or without disabilities.
Methods: A total of 147 parents were recruited for the study (71 had children with disabilities and 76 had children without disabilities) using convenience sampling. The World Health Organization Quality of Life Measure Abbreviated version (WHO-QOL BREF [HK]) was used to measure the QOL among the parents (Bonomi, Patrick, Bushnell et al., 2000; Leung, Tay, Cheng et al., 1997). The Wee Functional Independence Measure was used to measure the children's levels of disabilities. Other demographic data such as financial conditions and family background were also recorded.
Results: Social relationships and environmental domains of QOL differed significantly between the two groups of parents, but there were no significant differences in physical health and psychological domains of QOL between the two groups. Parental QOL and the disability levels of their children were positively correlated. Parents who have children with more severe disabilities were found to have lower scores in physical, psychological, and environmental domains. Children with severe disabilities are more physically demanding of their parents, who might feel more stress when taking care of them. Parents' physical and psychological well-being might directly affect their children.
Conclusion: This study indicates the need for parental support when providing intervention to their children with disabilities.

KEY WORDS: Quality of life • Parent • Disabled children • Disabilities

Introduction

According to The Developmental Disabilities Assistance and Bill of Rights Act of 1991, Public Law 98-527, USA, children with developmental disabilities are defined as follows: "severe chronic disability of a person attributable to a mental or physical impairment or a combination of both, manifested before the age of 22 years." This impairment is likely to continue indefinitely and result in substantial limitations of function in three or more of the following areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and financial self-sufficiency. These individuals also require special long-term or life-long interdisciplinary or generic care, treatment, or other services to be individually planned or coordinated (Azaula, Msall, Buck et al., 2000; Leonard, Johnson & Brust, 1993).

Children's disabilities and distresses may burden their family members, especially their parents, who are their long-term caregivers (Cooper, 1991; Ellis, Upton & Thompson, 2000; Elmstahl, Malmberg & Annerstedt, 1996). Children with disabilities may affect their parents' quality of life (QOL) (Evans, Dingus & Haselkorn, 1993). Parents might need to spend most of their time taking care of their disabled child, especially if the child has severe disabilities, and the parents

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are then unable to engage in other activities, curtailing their social life and negatively affecting their QOL.

Previous research findings also indicate that the more intensive the care or level of assistance given to the disabled child, the lower the QOL of the caregiver (Unalan, Gencosmanoglu, Akgun et al., 2001). A decrease in parental care and support to the disabled child might occur (Wright, 1993), eventually resulting in a vicious cycle for the disabled child that affects the child's QOL, health, and well-being (Glasscock, 1997).

Children with disabilities create special challenges for parents. This study was conducted to gain a better understanding of the QOL of parents with disabled children. The results of this study may help rehabilitation professionals better understand the problems of disabled children and their impact on their parents' QOL.

Methods

This study used a cross-sectional study design based on power analysis and sample size: a sample size of 64 is needed in each group to yield a power of 0.80, effect size of 0.50, and significance level of 0.05 (Cohen, 1988). A total of 76 parents were recruited from a primary school and another 71 parents were recruited from a special school for the disabled using a convenience sampling method. The children were 6 to 12 years of age. Approval from the Ethical Research Committee of The Hong Kong Polytechnic University was granted prior to the study. All parents signed the informed consent form prior to the commencement of the assessments and interviews. The WHO-QOL BREF (HK) questionnaire was then distributed to the parents for completion, and a telephone interview with the parents was conducted afterwards to obtain the children's functional independence based on the Wee Functional Independence Measure (Wee-FIM). Similar procedures were used in a previous study and the results were reported to be valid and reliable (Wong, Wong, Chan et al., 2002).

The WHO-QOL BREF (HK) questionnaire was used because it was developed and translated by a multidisciplinary team in Hong Kong, so that it is culturally related to the local population (Leung, Tay, Cheng et al., 1997). The Wee-FIM was used in this study because it is quick and easy to administer; it assesses the functional status of children through interiews with their parents. It was developed to evaluate the comprehensive functional independence or burden of care of children using 18 assessment items, including self-care, mobility, and cognitive and social communication (Ottenbacher, Msall, Lyon et al., 1997; Ottenbacher, Msall, Lyon et al., 2000).

Results

Of the 147 parents recruited, 71 (48%) had children with developmental disabilities (group A) and 76 (52%) had children without disabilities (group B). Their demographic data are presented in Table 1. Baseline comparisons using the Chi-squared test did not show statistical differences between the two groups in terms of gender, level of education, marital status, work status and religion (Table 2). The *t* test was used to compare parental age, monthly family income, and children's ages, with no significant differences shown between the two groups (Table 3). The two groups were thus considered homogeneous for comparison.

The children's disabilities included cerebral palsy, mental retardation, Down syndrome, and developmental delay (Table 4). The independent *t* test was used to compare QOL between the two parent groups. Parents of children with developmental disabilities scored lower in overall QOL as measured with the WHO-QOL BREF (HK) (Table 5). Scores for all four domains (physical health, psychological health, social relationships, and environment) were lower in group A parents than in group B parents. The social relationships and environment domains differed significantly between the two groups.

For group A parents, the functional independence of their children was significantly correlated with their QOL. The three domains of parental QOL, i.e. physical health ($r = 0.361$), psychological health ($r = 0.371$), and environment ($r = 0.358$), had strong correlation with the severity of the children's disability, but there was no significant correlation with social relationships ($r = 0.170$) (Table 6). Parents of children with severe disabilities seemed to have a lower QOL compared to parents of children with milder disabilities.

Discussion

Parents of children with developmental disabilities had lower QOL scores compared to parents of similar backgrounds who had children without disabilities. There seemed to be a negative impact when a child with disability was born. Previous studies indicate that these parents often feel depressed and disappointed when they have a child with a disability (Li-Tsang, Yau & Yuen, 2001; Yau & Li-Tsang, 1999; Schneider, Gurucharri, Gutierrez et al., 2001). While it takes time for them to accept their children, as the children grow, parents might feel pressure from society, especially on the occasions when their children exhibit unpredictable misbehaviour in public, such as screaming. In order to avoid these embarrassments, parents sometimes refrain from social activities. Thus, they limit their social networks (Kazak & Marvin, 1984; Kazak & Wilcox, 1984).

Table 1. Demographic data for parents of disabled children (group A) and non-disabled children (group B)

	Group A *n* (%)	Group B *n* (%)
Total no. of parents	71 (48.3)	76 (51.7)
Age, yr		
15–25	2 (2.8)	0 (0)
26–30	0 (0)	4 (5.3)
31–35	9 (12.7)	11 (14.5)
36–40	33 (46.5)	42 (55.3)
41–45	15 (21.1)	14 (18.4)
≥ 46	12 (16.9)	5 (6.6)
Gender		
Female	55 (77.5)	63 (82.9)
Male	16 (22.5)	13 (17.1)
Marital status		
Married	64 (90.1)	70 (92.1)
Divorced	7 (9.9)	6 (7.9)
Education		
Illiterate	2 (2.8)	0 (0)
Primary	20 (28.2)	18 (23.7)
Secondary	40 (56.3)	49 (64.5)
University or above	9 (12.7)	9 (11.8)
Work status		
Full-time	24 (33.8)	27 (35.5)
Part-time	7 (9.9)	7 (9.2)
Unemployed	40 (56.3)	42 (55.3)
Monthly family income, HK$		
≤ 5,000	5 (7.0)	3 (3.9)
5,001–10,000	19 (26.8)	20 (26.3)
10,001–15,000	21 (29.6)	12 (15.8)
15,001–20,000	11 (15.5)	16 (21.1)
20,001–25,000	2 (2.8)	13 (17.1)
≥ 25,001	13 (18.3)	12 (15.8)
Religious background		
Yes	21 (29.6)	26 (34.2)
No	50 (70.4)	50 (65.8)

Table 2. Baseline comparison (χ^2) between parents of disabled children (group A) and non-disabled children (group B)

	Value	*p**
Gender	0.486	0.486
Level of education	5.368	0.252
Marital status	0.034	0.983
Work status	0.065	0.968
Religion	0.428	0.513

*2-tailed. Level of significance: $p < 0.05$.

Some parents also avoid their relatives and friends, fearing that they may not understand their children's needs (Ayrault, 2001). According to past studies, parents spend much of their time caring for their children, taking them for assessment, therapy or medical treatment (Ayrault, 2001). As a result, their social life is interrupted and their QOL in this domain decreases; this is supported by the results of our study.

Previous studies have also reported that parents of disabled children face greater financial burdens than parents who have non-disabled children, as they need to pay for the health care and therapy services for their children (Singer & Powers, 1993; Yau & Li-Tsang, 1999). Parents have to place the special needs of their children above their own needs (Beckman, 1983; Byrne & Cunningham, 1985; McLinden, 1990; Hanline, 1991; Margalit & Ankonina, 1991; Hadadian, 1994; Mallow & Bechtel, 1999; Li-Tsang, Yau & Yuen, 2001). Thus, parents' psychological QOL may be indirectly lowered. Parents may have feelings of guilt and pessimism, and become aggressive. This will severely negatively affect their psychological health.

However, other studies indicate that some parents are able to develop a positive attitude toward their children who have disabilities (Li-Tsang, Yau & Yuen, 2001; Montgomery, Pers-

Table 3. Baseline comparison (*t* test) between parents of disabled children (group A) and non-disabled children (group B)

	n	Mean	SD	*t*	*p**
Age				1.540	0.126
Group A	71	4.3239	1.1311		
Group B	76	4.0641	0.9022		
Monthly family income				–1.329	0.186
Group A	71	3.2958	1.6422		
Group B	76	3.6410	1.5287		
Children's age				–0.326	0.745
Group A	71	3.9577	1.8780		
Group B	76	4.0513	1.6269		

*2-tailed. Level of significance: $p < 0.05$. SD = standard deviation.

Table 4. Demographic data of the children with disabilities (group A) and without (group B)

	Group A *n* (%)	Group B *n* (%)
Age, yr		
6–6 11/12	9 (12.7)	5 (6.6)
7–7 11/12	9 (12.7)	12 (15.8)
8–8 11/12	11 (15.5)	10 (13.2)
9–9 11/12	7 (9.9)	16 (21.1)
10–10 11/12	14 (19.7)	13 (17.1)
11–11 11/12	21 (29.6)	20 (26.3)
Diagnosis		
Cerebral palsy	22 (31.0)	0 (0)
Down syndrome	10 (14.1)	0 (0)
Mental handicap	11 (15.5)	0 (0)
Developmental delay	28 (39.4)	0 (0)

son & Ryden, 1996; Stoneman & Brody, 1981). Some manage to adjust their life situation by learning to adapt to and accept their child's disability. Some parents even learn to appreciate their children's special abilities (Gallagher, Cross & Scharfman, 1981; Yau & Li-Tsang, 1999). In this study, we did not find significant differences in the physical and psychological health domains between the two groups of parents. The reason for this might be related to the different coping mechanisms in parents of children with disabilities.

In the group of parents with children with disabilities, there were significant correlations between children's functional independence and parents' QOL in the physical health, psychological health and environmental domains. These results are consistent with the experiences reported by parents of disabled children in other studies (Cameron, Snowdon & Orr, 1992; Glasscock, 1997). Some parents suffered from low back pain and wrist pain as a result of assisting their children in daily chores such as transfer, toileting, and bathing. In view of the severe disabilities of their children, parents may become physically exhausted in the provision of intensive care and attention to their children. Some parents may develop chronic pain due to repetitive strain. Thus, parents' physical health QOL domain will be affected.

Parents of children with more severe disabilities may experience higher anxiety and stress levels (Browne & Bramston, 1996; Johnson, 2000; Leonard, Johnson & Brust, 1993). Parents might become depressed and frustrated over their children's minimal improvement or progress, even though they have been working very hard to train their children. Moreover, parents might worry about the future of their children when they become older and can no longer manage their children. This study showed strong correlation between the psychological health QOL domain and the children's functional performance.

There was a high correlation between the children's level of functional performance and their parents' QOL in the environment domain. Because of the intensive parental care and support that the disabled children needed, parents devoted most of their time to taking care of them. Parents therefore had less time and freedom to manage and control their own schedule and plans. The situation can become more severe when the child's level of function gradually deteriorates and they require more intensive care and attention. Parents' QOL in the environmental domain can be seriously affected. This warrants special attention and intervention when planning an intervention programme for children with disabilities.

Table 5. Comparison of quality of life between parents of disabled children (group A) and non-disabled children (group B)

	n	Mean	SD	*p**
Domain 1: physical health				
Group A	71	13.9960	2.2567	0.104
Group B	76	14.6090	2.2864	
Domain 2: psychological health				
Group A	71	13.3773	2.2211	0.094
Group B	76	14.0395	2.5136	
Domain 3: social relationships				
Group A	71	13.4085	1.8841	0.024†
Group B	76	14.1667	2.1197	
Domain 4: environment				
Group A	71	12.0493	2.3409	0.017†
Group B	76	12.9821	2.3427	

*2-tailed; †$p < 0.05$. SD = standard deviation.

Table 6. Correlation between group A parents' quality of life and the functional independence of their children

	Pearson's correlation coefficients				
	Domain 1 (physical)	Domain 2 (psychological)	Domain 3 (social relationships)	Domain 4 (environment)	WEE-FIM
Domain 1	1.000				
Domain 2	0.706*	1.000			
Domain 3	0.312*	0.372*	1.000		
Domain 4	0.658*	0.692*	0.351*	1.000	
Wee-FIM	0.361*	0.371*	0.170	0.358*	1.000

*$p < 0.01$, 2-tailed. Wee-FIM = Wee Functional Independence Measure.

The only domain that seemed to have little correlation with the level of children's disabilities was the social relationships domain. Previous studies have also indicated that parents' active participation in social activities has no strong correlation with the level of disabilities in their children (Yau and Li-Tsang, 1999; Li-Tsang, Yau & Yuen, 2001). In general, parents of children with disabilities are more withdrawn from society. However, previous reports have observed that some parents actively participate in parental self-help support groups. These parents tend to be educated, with higher intellectual function, stable family backgrounds, no financial difficulties, outgoing, confident, efficient, and motivated. Parents' attitudes, rather than their children's level of disabilities, seem to be the main determinant for active social participation (Atkin, 2000; Li-Tsang, Yau & Yuen, 2001). In this study, the correlation between parents' social relationships QOL domain and the level of disabilities of their children was low.

Conclusion

This study investigated the QOL among parents of children with and without developmental disabilities. The relationship between parental QOL and children's functional independence was evaluated. Results indicated that parents of children with disabilities had lower QOL scores in the social relationships and environment domains. Suitable intervention should be given to support these parents, to build a social network so that they can improve their social life. When children have more severe disabilities, the physical and psychological health QOL domains of their parents are also affected. Health care professionals should be more aware of the needs of this group of parents. More support and intervention should be offered, to enable them to enhance their physical and psychological well-being. Empowerment programmes such as coping skills training, stress management, positive thinking training, and self-help support groups should be organized for parents in need to help them release their stress and vent their feelings. It is believed that if the QOL of parents is improved, better parental care will result and further enhance the well-being of their children.

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